

Orthopedic Impairments/ Spina Bifida and Cerebral Palsy

Orthopedic Impairments

Definition: This term includes impairments caused by a congenital anomaly (e.g., club foot), impairments caused by disease (e.g., bone tuberculosis), and impairments from other causes (e.g., cerebral palsy). Children may have a physical disability as a result of deformities of the spine, muscles, bones, or joints, or as a result of neurological damage.

Spina Bifida

Definition: Spina Bifida is a condition that can result in mobility problems. Spina Bifida is a birth defect that results in an incomplete closure of the spinal column. In general, the three types of spina bifida are Spina Bifida Occulta, Meningocele, and Myelomeningocele. The term "Spina Bifida Manifesta" refers to the meningocele and myelomeningocele forms of Spina Bifida.

Incidence: Spina Bifida Manifesta affects approximately one of every thousand births; of these 4% will have the meningocele form and 96% will have the most severe form, Myelomeningocele.

Cerebral Palsy

Definition: Cerebral Palsy is a condition caused by damage to the brain, usually occurring before, during, or shortly following birth. Cerebral palsy is neither progressive nor communicable. It is not a disease and should never be referred to as such. It can range from mild to severe.

Incidence: Between 500,000 to 700,000 Americans have some degree of cerebral palsy. About 3,000 babies are born with the disorder each year and another 500 or so acquire it in the early years of life.

•Activities

- 1.) Elementary School Age
 - a.) Balance Problem
 - b.) Nick Joins In
 - c.) Learning Together
- 2.) Middle School Age
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- 3.) High School Age
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- Bibliography of Children's Literature & Audio Visual Materials
- Community Resource Numbers

ELEMENTARY SCHOOL

Balance Problem

Purpose: To promote empathy. Children will experience what it might be like to have a disability that causes difficulty with walking.

Materials: Balance beam or masking tape on the floor.

Activity: Many children with cerebral palsy and other orthopedic handicaps have a lot of trouble keeping their balance. How does it feel? Take the children one at a time and have them close their eyes. Spin them around. Have them open their eyes and immediately walk down the balance beam (or strip of tape on the floor).

Discussion: How would you feel if you always felt shaky when you walked? What equipment would you use to help you walk better and feel safer? (braces, crutches, walkers, crawlers, helmets, etc.)

Barnes, Ellen, Carol Berrigan, and Douglas Biklen. What's the Difference: Teaching Positive Attitudes Toward People with Disabilities. Syracuse, NY: Human Policy Press, 1978.

ELEMENTARY SCHOOL

Nick Joins In

Purpose: To promote an appreciation of differences and similarities among people and to help children identify and appreciate diversity.

Materials: Book: *Nick Joins In*, by Joe Lasker, pictures of children with and without disabilities, large white cardboard circle cut into "puzzle" pieces

Order from: The Disability Resource Library
12200 Academy Road, NE Suite 1212
Albuquerque, NM 87111
800-686-6049

Borrow from: Baltimore County Public Library
(contact your local branch)

or
The Resource Center for Families and Schools
410-887-5443

Activity:

(Before class) Assemble a collection of pictures of children with and without disabilities. Draw two large circles on separate pieces of white poster board. Cut one circle into enough pieces for each child in the class. Use the other circle as a template so that the children can reassemble their "puzzle" pieces into a circle.

1. Read aloud *Nick Joins In*.
2. Discuss with the children the following questions:
 - a) Why was Nick scared about going to his new school? What was he afraid of?
 - b) How did Nick's school get ready for him?
 - c) What kinds of questions did Nick's classmates ask him?
 - d) How did Nick help at school?
 - e) Who was Nick's friend?
 - f) How did Nick help his friends get the ball from the roof?
 - g) Do you think Nick likes school? Why or why not?
3. Similarities and Differences
 - a) Divide the children into cooperative learning groups of 4 or 5.
 - b) Provide each group with a picture of some children with and without disabilities.
 - c) Introduce the next activity with the following remarks: The children in these pictures are the same in many ways and different in other ways. How are the children the same? How are they different?
 - d) Give the children time to study the pictures carefully and talk about their conclusions within the groups.
 - e) Gather the children back together for a general discussion of the following questions: What are the children doing in the picture? Do the children look happy or sad? Do you see friends in the picture? What similarities did you notice? What differences did you notice? (If the children notice differences related to disability, talk about those differences and what causes them (e.g., Yes, that child is using crutches because his legs don't work well for walking and he needs some assistance.)

(Continued on next page)

4. Circle of Friends (This project may need to be completed over time.)

- a) Distribute a piece of the large circle to each child.
- b) Have the children color their pieces and write their first names on them with markers.
- c) Show the children the second large circle that you made. Put this circle on the floor and have the children take turns bringing up their puzzle pieces and try to put them together to form a circle.
- d) When all the pieces are assembled into a circle, glue them to the intact circle underneath. Talk about how all the pieces were different and how each piece was necessary to make a whole.

NOTE: If some children are absent, you may have to wait to complete the puzzle until all the pieces are finished. This is a good object lesson, reinforcing the whole idea that all of the children are necessary to complete the circle of friends.

- e) Label the completed puzzle "Circle of Friends" and display in the classroom.

Reinforcement Activities: Have the children bring in various kinds of fruits like apples, bananas, oranges, or pears. Wash and prepare the fruits for a fruit salad. As you eat the salad together, talk about how having all the different kinds of fruits makes the salad more interesting and more delicious. Other similar activities to reinforce the concept of the value of diversity could include making vegetable soup or fingerprint pictures. Read aloud books such as *My Friend Leslie* by Maxine Rosenberg or *Thinking Bit* by Susan Kuklin.

ELEMENTARY SCHOOL

Learning Together

Purpose: To provide students with first-hand experience in accommodating children with disabilities.

Materials: Map, litter bags, snacks (if appropriate), camera (optional-for reinforcement activity)

Activity:

People learn in different ways and get different kinds of pleasure out of the same activity. To include everyone, we have to plan ahead and think about the accommodations we might need to make so that everyone can have fun.

Arrange for your class to go on a walk with some children who have mobility disabilities or who have multiple disabilities (e.g., children who use wheelchairs, crutches, or walkers). The children with special needs who will be going on the walk may already be members of your class or may be invited guests from other classes or programs. In advance of the trip, ask the special educator who works with the special needs children who will be going on the walk to talk to your class about the necessary accommodations so that everyone can participate. Enlist some help for the walk so that all of the children who are participating can be properly supervised. (Arrange for a volunteer to take pictures of the children on their walk for the reinforcement activity below.)

Draw a large map of the route you plan to take on your walk. Put interesting landmarks on the map.

1. Planning A Walk

- Have the class look at the map of the area where you are planning to take Your walk. Where will we start and where will we end our walk? Should we take litter bags? Shall we pick up litter on our way?
- Have the special educator talk to the children about some of the obstacles they may encounter on the walk. Will there be Curb cuts so that wheelchairs can get through? Is any part of the walk especially hilly or bumpy? How long is the walk? Will it be too long for some of the people who have a hard time walking? Will the group need to go slowly? Is there someone who is going who has a hard time staying with the group? What can we do about that? How will we make sure that no one gets lost?
- What fun things might we see on Our walk? Should we bring snacks on Our walk? What shall we bring?

2. Class Story

- Write a class story about your walk, describing what everyone liked best and what was learned on the walk.
- If there were any problems or obstacles to be overcome on the walk, include those in the story as well.

Reinforcement Activity: Give each of the children in the class a photograph from the walk and have each child write a story about what is happening in the picture.

Reference: People Like Us, Disability Awareness Curriculum For Montana's Students, edited by: Katharine A. Keiker Parents, Let's Unite For Kids, Billings, Montana

MIDDLE SCHOOL

Clumsiness

Purpose: To help students understand that a person with a physical disability may or may not also have mental retardation. It is inappropriate to assume that someone who has coordination problems also has mental retardation.

Materials: Pair of thick socks, grab bag of common objects, shirts, sweaters, shoes, puzzles

Activity:

Some people have clumsy or awkward ways of moving, others have problems with fine motor coordination. This is because their muscles are weaker and need more time and practice at learning how to move. It's hard sometimes for children to understand that the way a person moves is the best way he or she knows. You might want to talk about this before these experiments.

- Each child puts a pair of thick socks on each hand. With the sock on, tie shoes and button up a shirt. Put puzzles together. Reach into a grab bag and try to identify a common object by touch. (They could try to string beads or use scissors, too.)
- Tie a ruler between the students' ankles so that their legs are stiff and apart from each other. Have the students walk down the halls and back, slowly. How would they feel if people laughed or stared at them, or if people imitated the way they walked?

Discussion:

Some people who have these kinds of problems have mental retardation. Their muscles are weaker and their coordination is poor. But, by no means, do all people with these problems have mental retardation. This is a big area of confusion for children and adults. You might discuss this problem in terms of the mistake of making assumptions about people. Can you assume that someone who can't use his or her hands has mental retardation? Can you assume that someone who can't walk well is doing it to amuse you? How should you react to a person with these problems?

MIDDLE SCHOOL

Case Study: Jessica

Purpose: To introduce the concept of accommodation, adaptation, and access as they relate to disability.

Materials: Copies of Jessica Case Study

Activity:

Provide definitions of the words:

accommodation: An accommodation is a way of modifying a task or assignment so that a person with a disability can participate in spite of whatever limitations the disability may impose. For example, when a child who has trouble remembering math facts is allowed to do math problems with a calculator, the use of the calculator is an accommodation which allows the child to work around his or her disability. With an accommodation, the child can still perform math problems, but he or she does so using a different method.

adaptation: Adaptation means developing devices or methods designed specifically to assist persons with disabilities to perform daily tasks. An adaptation is something specially designed which is not normally used by other people, while an accommodation is simply a change in routine or approach which may be used by people with or without disabilities. Examples of adaptation include special tools to reach stove knobs or specially designed equipment to access computers.

access: Access means removing barriers that disability, attitudes, or the environment may impose so that the person with a disability has an opportunity to participate.

Have students brainstorm all the different types of accommodations and adaptations that allow for "access"; for example, a curbcut allows an individual access to the sidewalk and therefore to his/her community. Other kinds of "curbcuts" include modifications and attachments to computers which make them accessible to persons with all sorts of disabilities. For someone with a vision impairment, a walking stick allows for mobility.

Discussion: Answer at least two of the following questions:

1. If you were Jessica's teacher, what would you do?
2. Do you think it is fair for Jessica to have a computer when no one else does? Why or why not?
3. Should Jessica be allowed to get good grades even though she does shorter assignments? Why or why not?
4. Is it fair for Jessica to have an aide? Why or why not?
5. Is it fair that Jessica receives more of the teacher's attention than some of the other students? Why or why not?

Reference: People Like Us, Disability Awareness Curriculum For Montana's Students, Edited by: Katharine A. Kelker. Parents Let's Unite For Kids, Billings, Montana.

Case Study: Jessica

Jessica, who has cerebral palsy, is in the seventh grade at Holmquist Middle School. Jessica attends all regular classes, but she has to have some accommodations and adaptations so that she can manage. Jessica uses a wheelchair and she needs an aide to help her use the bathroom. She can write using a pencil or pen, but writing is tiring for her. Jessica's teacher allows her to do shorter assignments so she will not have to write so much. Sometimes Jessica records her answers on tape. In addition, Jessica uses a lap top computer for taking notes in class. Some students find the clicking of Jessica's computer keys annoying. Other students think that it is not fair for Jessica to be able to use a computer in class when no one else is able to use a computer. Some students have complained to the teacher because they think Jessica is getting too much special treatment. They are especially annoyed because she gets good grades when she does not have to do as much work as the rest of the class. Jessica's teacher is not sure what to do. She wants to treat all of the students fairly, yet she knows that Jessica needs some special help.

MIDDLE SCHOOL

Problems in Muscle Control

Purpose: To help students understand the difficulties encountered by someone who has a disability, such as cerebral palsy, that affects movement or posture.

Materials: Blanket, towels, wobbly chair

Activity:

People with cerebral palsy are often floppy or their bodies seem rigid. If you aren't familiar with CP, this might look scary at first. These experiments will help children understand how distracting and difficult it can be to have these problems.

- Lie down on the floor. Try to get up without using your head.
- Get tightly wrapped in a blanket. Try to roll over.
- Have the students sit in a small group while you read a story or carry on a discussion. While they are listening, have them keep dropping their heads loosely. Can they follow what's going on?
- Sit in a wobbly chair (or some other precarious position that you can devise). After a while, notice how much attention and strength you must spend on keeping your balance.

Barnes, Ellen, Carol Berrigan, and Douglas Biklen. What's the Difference: Teachings Positive Attitudes Toward People with Disabilities. Syracuse, NY: Human Policy Press, 1978.

HIGH SCHOOL

Extra Weight

Purpose: To simulate the additional weight involved for children who wear leg braces or other prosthesis. To increase students awareness and understanding of children with physical disabilities that require the use of adaptive devices.

Materials: Sandbags with straps to fit wrists

Activity:

Children who wear braces or artificial limbs are carrying around a lot of extra weight. To feel how tiring this is, have the students take turns walking around the room three times with sandbags hanging at the wrists, arms out-stretched. In this, and similar experiments, talk with your students about how much patience somebody has to have to keep working on things that, to many, are automatic like walking, keeping balance, etc.

Barnes, Ellen, Carol Berrigan, and Douglas Biklen. What's the Difference: Teaching Positive Attitudes Toward People with Disabilities. Syracuse, NY: Human Policy Press, 1978.

HIGH SCHOOL

Experiencing Barriers

Purpose: To allow students to experience obstacles and barriers that people with disabilities sometimes experience.

Materials: Accessibility Checklists, 6-8 wheelchairs (Try your local hospital to see if they can loan the wheelchairs or call Chesapeake Rehab at 410-298-4555 and ask for Clarissa Schoen.)

Activity: Accessibility refers to modifications which allow a person with a disability to gain admittance to a facility or to participate in an activity in spite of whatever limitations the disability may present. For example, a building becomes accessible when it is modified or designed so that persons with limited mobility (in wheelchairs or with crutches) can move into and around the building without encountering barriers. An accessible sport might be a T-ball game in which the rules have been modified to allow a child with cerebral palsy to participate in spite of his or her physical limitations (e.g., when the child with CP hits the ball, another team member can push the child in a wheelchair around the bases).

1. Using real wheelchairs (6-8) and the Accessibility Survey in the resource packet, divide the students into "accessibility groups."
2. Have the students tour their high school to determine if a student with a physical disability would have equal access to the classrooms, cafeteria, gym, locker room, music, art, technology education facilities, bathrooms, hallways. Is there an elevator? Are stairs an obstacle?
3. If the school building is large, divide the building into sections and send one group to each section.
4. When students have finished their survey, the class should reconvene to discuss the questions below.
 - How accessible is your school building?
 - What parts of the school are the most accessible? Least accessible?
 - What recommendations do students have for making their school more accessible?
5. Set up a basketball relay in the gym. Have students break into two groups. Each person must "roll" down the court with a basketball in their lap and shoot a basket, then return to their line so the next person can go. The team that finishes first and/or makes the most baskets wins.

Reference: People Like Us, Disability Awareness Curriculum For Montana's Students, Edited by : Katharine A. Kelker; Parents, Let's Unite For Kids, Billings, Montana

Accessibility Survey

A barrier is something that makes it difficult or impossible for a person who has a disability to get into or around in a building. Is our school barrier free? Use this checklist to find out.

YES NO

- | | | |
|--------------------------|--------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <input type="checkbox"/> | <input type="checkbox"/> | 1. Does the main entrance to the school have a ramp? |
| <input type="checkbox"/> | <input type="checkbox"/> | 2. Are the doorknobs of all main doors 3 feet from the ground so people in wheelchairs can reach them? |
| <input type="checkbox"/> | <input type="checkbox"/> | 3. Do the hallways have handrails to help people walk? |
| <input type="checkbox"/> | <input type="checkbox"/> | 4. Are there parking spaces reserved for people with disabilities? Are these parking spaces near the building entrance? Are they 12 feet wide? Are there at least 2 out of every 100 parking spaces reserved for people with disabilities? (All answers must be yes to receive credit.) |
| <input type="checkbox"/> | <input type="checkbox"/> | 5. Are there curb cuts so that people with wheelchairs or with baby carriages or shopping carts pass easily? |
| <input type="checkbox"/> | <input type="checkbox"/> | 6. Are there tactile markings (marking which can be felt) cut into the sidewalk to warn people who have visual impairments? |
| <input type="checkbox"/> | <input type="checkbox"/> | 7. Does the school have an elevator? |
| <input type="checkbox"/> | <input type="checkbox"/> | 8. If there is an elevator, does it have braille markers for the floor buttons? |
| <input type="checkbox"/> | <input type="checkbox"/> | 9. Does the elevator have light and bell signals to help people who have visual or hearing impairments to know when the elevator is ready? |
| <input type="checkbox"/> | <input type="checkbox"/> | 10. Is there at least one accessible bathroom with a doorway that is at least 33 inches wide? |
| <input type="checkbox"/> | <input type="checkbox"/> | 11. Are the sinks in the accessible bathroom low enough to be reached from a wheelchair? |
| <input type="checkbox"/> | <input type="checkbox"/> | 12. Are there drinking fountains which are no more than 36 inches from the floor? |
| <input type="checkbox"/> | <input type="checkbox"/> | 13. Are there grab bars in the bathroom stalls so that people can lift themselves from a wheelchair to the toilet and back again? |
| <input type="checkbox"/> | <input type="checkbox"/> | 14. Are there accessible public telephones in the building? |
| <input type="checkbox"/> | <input type="checkbox"/> | 15. Are the fire alarms low enough for people in wheelchairs to use them? |
| <input type="checkbox"/> | <input type="checkbox"/> | 16. Are some windows in the building 24 to 28 inches from the floor so that people who are short and people who use wheelchairs can see out? |
| <input type="checkbox"/> | <input type="checkbox"/> | 17. Are the aisles in the classroom at least 32 inches wide so that people who use wheel chairs, crutches, canes, or walkers can get around easily? |
| <input type="checkbox"/> | <input type="checkbox"/> | 18. Are there picture signs to show the purpose of each room so that people who cannot read will know where to go? |

Home Accessibility Survey

Directions: Is your home accessible to persons with disabilities? Could you accommodate a person in a wheelchair as a guest? Survey your home and answer the following questions.

YES

NO

- | | | |
|--------------------------|--------------------------|----------------------------------------------------------------------------------------------------------------------------------------------|
| <input type="checkbox"/> | <input type="checkbox"/> | 1. Can a person in a wheelchair reach your front door after parking his or her car? Is there a sidewalk or driveway leading up to your door? |
| <input type="checkbox"/> | <input type="checkbox"/> | 2. Is the entrance to your home accessible to a person in a wheelchair? |
| <input type="checkbox"/> | <input type="checkbox"/> | 3. Are there any steps into your kitchen, family room, living room or bath room? Is your home split level in design? |
| <input type="checkbox"/> | <input type="checkbox"/> | 4. Is the door to your bathroom at least 36 inches wide? Would a person in a wheelchair be able to use the toilet and sink in your bathroom? |
| <input type="checkbox"/> | <input type="checkbox"/> | 5. Are the archways and hallways in your home wide enough to accommodate a wheelchair? |
| <input type="checkbox"/> | <input type="checkbox"/> | 6. Are the floor surfaces in your home smooth and hard? The carpets tightly woven and flat? |
| <input type="checkbox"/> | <input type="checkbox"/> | 7. Is there room around your dining table to accommodate a wheelchair? |
| <input type="checkbox"/> | <input type="checkbox"/> | 8. Is there room in your living room to include a person in a wheelchair at an informal party? |



CEREBRAL PALSY

◆ Definition ◆

Cerebral palsy is a condition caused by damage to the brain, usually occurring before, during or shortly following birth. "Cerebral" refers to the brain and "palsy" refers to a disorder of movement or posture. Cerebral palsy is neither progressive nor communicable. It is also not "curable" in the accepted sense, although education, therapy, and applied technology can help persons with cerebral palsy lead productive lives. It is not a disease and should never be referred to as such. It can range from mild to severe.

The causes of cerebral palsy include illness during pregnancy, premature delivery, or lack of oxygen supply to the baby. It may occur early in life as a result of an accident, lead poisoning, viral infection, child abuse, or other factors. Chief among the causes is an insufficient amount of oxygen or poor flow of blood reaching the fetal or newborn brain. This can be caused by premature separation of the placenta, an awkward birth position, labor that goes on too long or is too abrupt, or interference with the umbilical cord. Other causes may be associated with premature birth, RH or A-B-O blood type incompatibility between parents, infection of the mother with German measles or other viral diseases in early pregnancy, and microorganisms that attack the newborn's central nervous system. Lack of good prenatal care may also be a factor. A less common type is acquired cerebral palsy: Head injury is the most frequent cause, usually the result of motor vehicle accidents, falls, or child abuse.

◆ Incidence ◆

Between 500,000 - 700,000 Americans have some degree of cerebral palsy. About 3,000 babies are born with the disorder each year, and another 500 or so acquire it in the early years of life.

◆ Characteristics ◆

There are three main types of cerebral palsy: spastic—stiff and difficult movement; athetoid—involuntary and uncontrolled movement; and ataxic—disturbed sense of balance and depth perception. There may be a combination of these types for any one individual. Other types do occur, although infrequently.

Cerebral palsy is characterized by an inability to fully control motor function. Depending on which part of the brain has been damaged and the degree of involvement of the central nervous system, one or more of the following may occur: spasms; tonal problems; involuntary movement; disturbance in gait and mobility; seizures; abnormal sensation and perception; impairment of sight, hearing, or speech; and mental retardation.

◆ Developmental, Educational, and Employment Implications ◆

Early identification of cerebral palsy can lessen developmental problems and lead to appropriate intervention when it helps the most. Early intervention programs are family-centered, and professionals and families work together with the child in specific activities. Educators, physical and occupational therapists, social workers, speech-language pathologists, psychologists, and physicians can assist families by providing information and education.

Activities for children with cerebral palsy may include:

- speech and language therapy;
- occupational therapy;
- physical therapy;
- medical intervention;
- family support services;
- early education; and
- assistive technology.

CEREBRAL PALSY

◆ Organisations ◆

As a child gets older and begins formal schooling, the intensity of services will vary from individual to individual. Persons with cerebral palsy are usually able to attain a substantial degree of independence but, in some cases, may need considerable assistance. Services for the school-age child may include continuing therapy, regular or special education, counseling, technical support, community integration opportunities, recreation, and possible personal attendants. A key factor seems to be a supportive family. People extensively affected by cerebral palsy can still be highly functional and independent. The HEATH Resource Center (the clearinghouse on postsecondary education for individuals with disabilities) states that a significant number of students with cerebral palsy are enrolled in colleges and universities.

Important advances have taken place in the last 15 years which have had a great effect on the long-term well-being of children born with cerebral palsy. Advanced technology, including computers and engineering devices, has been applied to the needs of persons with cerebral palsy. Technological innovations have been developed in the areas of speech and communication, self-care, and adapting living arrangements and work sites. The future may bring even more significant applications.

Another important development has been the increased ability of persons with disabilities, including those who have cerebral palsy and other severe disabilities, to live independently in the community. Adults with cerebral palsy are now living, with or without assistance, in their own apartments or townhouses. Independent Living Centers have also proven to be important resources for persons with disabilities.

◆ Resources ◆

Geralis, E. (1998). *Children with cerebral palsy: A parent's guide* (2nd ed.). Bethesda, MD: Woodbine House. (Telephone: 1-800-843-7323.)

Weiss, S. (1993). *Each of us remembers: Parents of children with cerebral palsy answer questions*. Washington, DC: United Cerebral Palsy Associations, Inc. (See UCPA telephone number and address below.)

United Cerebral Palsy Associations, Inc.
1660 L Street, N.W., Suite 700
Washington, D.C. 20036
(202) 776-0406; (202) 973-7197 (TTY)
(800) 872-5827 (V/TTY)
E-mail: ucpanatl@ucpa.org
URL: <http://www.ucpa.org>

Independent Living Research Utilization Project
The Institute for Rehabilitation and Research
2323 South Sheppard, Suite 1000
Houston, TX 77019
(713) 520-0232; (713) 520-5136 (TTY)
E-mail: ilru@ilru.org
URL: <http://www.ilru.org>

Easter Seals—National Office
230 West Monroe Street, Suite 1800
Chicago, IL 60606-4802
(312) 726-6200; (312) 726-4258 (TTY)
1-800-221-6827
E-Mail: nessinfo@seals.com
URL: <http://www.easter-seals.org>

National Rehabilitation Information Center (NARIC)
8455 Colesville Road, Suite 935
Silver Spring, MD 20910-3319
(301) 588-9284 (V); (301) 495-5626 (V/TTY)
1(800)346-2742
URL: <http://www.naric.com/naric>

FS2, February 1999

Publication of this document is made possible through Cooperative Agreement #H326N980002 between the Academy for Educational Development and the Office of Special Education Programs of the U.S. Department of Education. The contents of this document do not necessarily reflect the views or policies of the Department of Education, nor does mention of trade names, commercial products, or organizations imply endorsement by the U.S. Government.

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SPINA BIFIDA

◆ Definition ◆

Spina Bifida means cleft spine, which is an incomplete closure in the spinal column. In general, the three types of spina bifida (from mild to severe) are:

1. *Spina Bifida Occulta*: There is an opening in one or more of the vertebrae (bones) of the spinal column without apparent damage to the spinal cord.
2. *Meningocele*: The meninges, or protective covering around the spinal cord, has pushed out through the opening in the vertebrae in a sac called the "meningocele." However, the spinal cord remains intact. This form can be repaired with little or no damage to the nerve pathways.
3. *Myelomeningocele*: This is the most severe form of spina bifida, in which a portion of the spinal cord itself protrudes through the back. In some cases, sacs are covered with skin; in others, tissue and nerves are exposed. Generally, people use the terms "spina bifida" and "myelomeningocele" interchangeably.

◆ Incidence ◆

Approximately 40% of all Americans may have spina bifida occulta, but because they experience little or no symptoms, very few of them ever know that they have it. The other two types of spina bifida, meningocele and myelomeningocele, are known collectively as "spina bifida manifesta," and occur in approximately one out of every thousand births. Of these infants born with "spina bifida manifesta," about 4% have the meningocele form, while about 96% have myelomeningocele form.

◆ Characteristics ◆

The effects of myelomeningocele, the most serious form of spina bifida, may include muscle weakness or paralysis below the area of the spine where the incomplete closure (or cleft) occurs, loss of sensation below the cleft, and loss of bowel and bladder control. In addition, fluid may build up and cause an accumulation of fluid in the brain (a condition known as hydrocephalus). A large percentage (70%-90%) of children born with myelomeningocele have

hydrocephalus. Hydrocephalus is controlled by a surgical procedure called "shunting," which relieves the fluid buildup in the brain. If a drain (shunt) is not implanted, the pressure buildup can cause brain damage, seizures, or blindness. Hydrocephalus may occur without spina bifida, but the two conditions often occur together.

◆ Educational Implications ◆

Although spina bifida is relatively common, until recently most children born with a myelomeningocele died shortly after birth. Now that surgery to drain spinal fluid and protect children against hydrocephalus can be performed in the first 48 hours of life, children with myelomeningocele are much more likely to live. Quite often, however, they must have a series of operations throughout their childhood. School programs should be flexible to accommodate these special needs.

Many children with myelomeningocele need training to learn to manage their bowel and bladder functions. Some require catheterization, or the insertion of a tube to permit passage of urine.

The courts have held that clean, intermittent catheterization is necessary to help the child benefit from and have access to special education and related services. A successful bladder management program can be incorporated into the regular school day. Many children learn to catheterize themselves at a very early age.

In some cases, children with spina bifida who also have a history of hydrocephalus experience learning problems. They may have difficulty with paying attention, expressing or understanding language, and grasping reading and math. Early intervention with children who experience learning problems can help considerably to prepare them for school.

Mainstreaming, or successful integration of a child with spina bifida into a school attended by nondisabled young people, sometimes requires changes in school equipment or the curriculum. Although student placement should be in the least restrictive environment the day-to-day school pattern also should be as "normal" as possible. In adapting the school setting for the child with spina bifida, architectural factors should be considered.

SPINA BIFIDA

Section 504 of the Rehabilitation Act of 1973 requires that programs receiving federal funds make their facilities accessible. This can occur through structural changes (for example, adding elevators or ramps) or through schedule or location changes (for example, offering a course on the ground floor).

Children with myelomeningocele need to learn mobility skills, and often require the aid of crutches, braces, or wheelchairs. It is important that all members of the school team and the parents understand the child's physical capabilities and limitations. Physical disabilities like spina bifida can have profound effects on a child's emotional and social development. To promote personal growth, families and teachers should encourage children, within the limits of safety and health, to be independent and to participate in activities with their nondisabled classmates.

◆ Resources ◆

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Spina Bifida Association of America. (1996). *Publications list*. Washington, DC: Author. (See address below.)

◆ Organizations ◆

Spina Bifida Association of America
4590 MacArthur Boulevard, Suite 250
Washington, DC 20007
(202) 944-3285
1-800-621-3141 (Toll Free)
E-Mail: sbaa@sbaa.org
URL: <http://www.sbaa.org>

March of Dimes Birth Defects Foundation
1275 Mamaroneck Avenue
White Plains, NY 10605
(914) 428-7100
E-mail: resourcecenter@modimes.org
URL: <http://www.modimes.org>

Easter Seals—National Office
230 West Monroe Street, Suite 1800
Chicago, IL 60606
(312) 726-6200
1-800-221-6827; (312) 726-6200
(312) 726-4258 (TTY)
E-Mail: nessinfo@seals.com
URL: <http://www.easter-seals.org>

National Rehabilitation Information Center (NARIC)
8455 Colesville Road, Suite 935
Silver Spring, MD 20910-3319
(301) 588-9284; (301) 495-5626 (V/TTY)
1-800-227-0216 (Toll Free)
URL: <http://www.naric.com/naric>

FS12, February 1999

Publication of this document is made possible through Cooperative Agreement #H326N980002 between the Academy for Educational Development and the Office of Special Education Programs of the U.S. Department of Education. The contents of this document do not necessarily reflect the views or policies of the Department of Education, nor does mention of trade names, commercial products, or organizations imply endorsement by the U.S. Government.

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Accessibility Facts

The following are suggestions on how to make buildings more accessible. Building codes vary from community to community and regulations differ for new and existing buildings; therefore, it is important to confirm accessibility standards with local building inspectors.

- Designate conveniently located parking spaces that are clearly marked for use only by persons with disabilities. Spaces should be 8 feet wide with an adjacent 5 foot wide access aisle to give persons who use wheelchairs access to their cars and the building.
- Curb ramps should be at least 36 inches wide with a slope no greater than 1 inch in 12 inches. Handrails provide additional help.
- Hallways should have 64 inches of clearance to allow persons who use wheelchairs to pass one another.
- Doors should be easy to operate with an opening of at least 32 inches and thresholds rising no greater than 1/2 inch.
- Ramps or elevators should be provided for access to multi-level areas.
- Drinking fountains should be mounted so that the spout is not more than 36 inches from the floor.
- Wall telephones should hang no more than 54 inches from the floor. Volume control handset equipment should be installed on the telephone for persons with hearing impairments.
- Accessible bathrooms should include an entrance door clearance of 32 inches, top of toilet 17 inches from the floor, bars on both sides of the toilet stall extending a maximum of 36 inches from the floor, faucets that are easily accessible and operable, and mirrors hung a maximum of 40 inches from the floor.
- Floor surfaces should be smooth surfaces or hard or tightly woven, slip resistant carpet.

"Disability-Myths"

People with Disabilities have been the subject of many myths and misconceptions which interfere with their acceptance into the mainstream of society. To help deflate some of the major myths about disabilities, this information which appears in the "Disabilities Resource Guide" of the KIDS Project, Center for Independent Living, Berkeley, California, is presented.

Prevalent Myths about People with Orthopedic Impairments

- MYTH: Children with orthopedic impairments also have mental retardation.
FACT: This is generally not true. Orthopedic impairment means difficulty with movement.
- MYTH: Children with Spina Bifida also always have mental retardation.
FACT: Children born with Spina Bifida, but without Hydrocephalus, usually do not have mental retardation. Retardation may result if Hydrocephalus is not controlled.
- MYTH: Because Cerebral Palsy means brain damage, it also means mental retardation.
FACT: In some cases, the damage can extend to the intellectual part of the brain. In other cases, intelligence is normal even though performance may be hampered.
- MYTH: When a person has difficulty in speaking, it means he has mental retardation.
FACT: There is no relationship between articulation skills (ability to speak) and intelligence.
- MYTH: It helps to speak loudly and to enunciate clearly to a person who has difficulty with speech.
FACT: Difficulty in speaking does not mean difficulty in hearing.
- MYTH: Don't allow a child with orthopedic impairments to become frustrated. Be ready to help at a moment's notice.
FACT: Every child needs to work with challenges. Through this process you, the teacher, will find out what each child's capability is. Be an observer, and let your own sensitivity to each child's needs be your guide.
- MYTH: A child with orthopedic impairments should never be allowed to fail.
FACT: If you don't allow for failure, you don't allow for successes. Physical and intellectual challenges are important for everyone.
- MYTH: A person with orthopedic impairments will never live independently as an adult.
FACT: The vast majority of people with orthopedic impairments can and do live independently. In some cases, adaptations are made or attendants are hired to provide needed assistance.
- MYTH: Children with orthopedic impairments are sickly.
FACT: Orthopedic impairment is not an illness, nor is it contagious.
- MYTH: All people who use wheelchairs spend all their time in a wheelchair.
FACT: Many will be able to walk short distances with and without aids (crutches, walkers) and others may crawl. However, a wheelchair is used because it makes mobility easier for long distances.
- MYTH: It is rude to stare and ask questions about a person's disability.
FACT: If people are not allowed to ask questions, the disability becomes mystical and fearsome and therefore isolating.

Quiz

Write "T" for True or "F" for False on the line in front of each statement.

- _____ 1. People with physical disabilities do not belong in our society.
- _____ 2. People with physical disabilities have mental retardation.
- _____ 3. All people with physical disabilities use wheelchairs.
- _____ 4. All people with physical disabilities must accept menial jobs.
- _____ 5. People with physical disabilities cannot hold professional jobs.
- _____ 6. People with physical disabilities do participate in athletics.
- _____ 7. People with physical disabilities can attend regular schools and colleges.
- _____ 8. People with physical disabilities can function easily in society.
- _____ 9. People with physical disabilities can make telephone calls from public phone booths.
- _____ 10. People with physical disabilities cannot become well known.
- _____ 11. People with physical disabilities cannot be integrated into society.
- _____ 12. Normal people are aware of the problems people with physical disabilities face.
- _____ 13. A person who cannot walk can go swimming.
- _____ 14. People with disabilities have feelings like everyone else.
- _____ 15. People with physical disabilities are as smart as everyone else.
- _____ 16. The architecture of buildings can hinder a person with physical disabilities.
- _____ 17. People who use wheelchairs can dress themselves.
- _____ 18. People are sometimes afraid of people with disabilities.
- _____ 19. A person who uses a wheelchair can drive a car.

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RESOURCE ORGANIZATIONS

State/National Resource Organizations

Easter Seal Society of Maryland
3700 4th Street
Baltimore, MD 21225
800-221-0134

Association for Persons with Severe
Handicaps
29 W. Susquehanna Avenue
Suite 210
Baltimore, MD 21204
410-828-8274

Spina Bifida Association of America
4590 MacArthur Blvd., NW #250
Washington, DC 20007-4226
800-621-3141

United Cerebral Palsy
1660 L Street NW
Suite 700
Washington, DC 20036
800-872-5827

National Rehabilitation Information
Center
8455 Colesville Road, Suite 935
Silver Spring, MD 20910-3319
800-346-2742

Local Organizations

Division of Rehabilitation Services
410-556-9381

MSDE
Dave Thompson
410-767-0430

The League
410-323-0500

United Cerebral Palsy
of Central Maryland
410-484-4540

For an expanded list of recommended films, literature, and resources on disabilities, send a self-addressed, stamped envelope to:
National Easter Seal Society, FRIENDS WHO CARE Resource List, 70 East Lake Street, Chicago, IL 60601.